



HDSA 2019 ANNUAL REPORT



GREETINGS!



*E.J. Garner, Chair, HDSA Board of Trustees and
Louise Vetter, HDSA President and CEO*

Dear Friends of HDSA,

Though 2019 may seem long ago, at times of uncertainty it's often helpful to reflect on the strength and health of recent times. **The 2019 Annual Report for the Huntington's Disease Society of America (HDSA)** is a clear reminder of how strong we are as a community united in the fight against Huntington's disease.

2019 was one of HDSA's most successful years ever. Thanks to the generous contributions from people like you, HDSA is growing in every aspect of our mission services, providing more support to families affected by HD. Importantly, the strides we made in 2019 positioned us to grow in 2020 despite the unforeseen challenges of COVID-19.

In 2019, we expanded the HDSA Centers of Excellence program to 47 facilities and 6 clinical sites across America where more families can receive expert care. With new Centers in California, Illinois, New York and North Dakota, HDSA supported comprehensive HD care locations in 53 clinics in 31 states, plus the District of Columbia. HDSA awarded a total of \$1.4 million to the Centers of Excellence program, an almost eleven percent increase in funding from 2018, and set us up for further expansion of care in 2020.

A year ago in June of 2019, HDSA welcomed Allison Bartlett, Esq. to serve as HDSA's Manager of Disability Programs. With her unique HD-focused experience, Allison is assisting countless families through the complex disability process. By hosting Disability Chats online and providing online resources to help families take advantage of federal benefits, she provides practical insight into the US Social Security Administration process and what is needed for approval.

Additionally, last year saw incredible growth in our support programs for youth impacted by HD.

Thanks to the Griffin Foundation, we welcomed two youth-focused social workers to the HDSA team. Katie Dykman, LISW and Jessica Marsolek, LGSW are experienced professionals trained to serve young people and respond to the unique needs of children, teens and young adults impacted by HD.

And this is just the tip of the iceberg... your contributions have allowed HDSA to get more hands on deck and improve our tremendous support programs even more. **HDSA's telehealth program, online support groups, HD Trialfinder and helpline are FREE for everyone affected by HD because of you.**

HDSA continues to be a world leader in supporting HD research. In 2019, we funded more HD science than ever before, including more than \$1.4 million in direct grants to scientists. We also continued to cultivate strong relationships with leading bio-pharmaceutical partners to ensure that the HD family voice resonates in drug development so that potential therapies are studied as quickly as possible.

As we continue to push forward, we cannot do this without your continued support. Whether it is a financial contribution, enrolling in a clinical trial, sharing a story on social media or just talking about HD in your community, we are all in this together.

Thank you and stay safe!

E.J. Garner
Chair, Board of Trustees

Louise Vetter
President & CEO

2019 HIGHLIGHTS

HDSA CENTERS OF EXCELLENCE GROW TO 47 SITES ACROSS THE U.S.

In 2019 HDSA announced that forty-seven outstanding Huntington's disease care facilities with six satellite sites were awarded the designation of HDSA Centers of Excellence. This was an increase from 43 in 2018, and from just 20 in 2015. The four new 2019 Centers of Excellence are: OSF HealthCare Illinois Neurological Institute (Peoria IL), Sanford Health, (Fargo, North Dakota), University of Buffalo (New York) and University of California, Irvine. The HDSA Centers of Excellence are multi-disciplinary care teams with expertise in Hunting-

ton's disease that share an exemplary commitment to bringing comprehensive care.

In December, HDSA awarded four grants under a new research initiative, the HDSA Center of Excellence Clinical Research Pilot Program. These grants, totaling \$50,000, represent HDSA's patient-centric research focus by fostering novel clinical research projects within the HDSA Center of Excellence network.

[Learn more at HDSA.org/COE](https://www.hdsa.org/COE)



OSF HealthCare Illinois
Neurological Institute (Peoria, Illinois)



Sanford Health,
(Fargo, North Dakota)



HDCARE Clinic, Gottschalk Medical Plaza,
University of California, Irvine



UBMD Neurology,
University of Buffalo (New York)

Huntington's Disease
Society of America
**Centers of
Excellence**



2019 HUMAN BIOLOGY PROJECT FELLOWSHIPS

In October of 2019, HDSA awarded five grants under the Society's largest research initiative, the **HDSA Huntington's Disease Human Biology Project**. These grants, totaling \$575,000, represent HDSA's patient-centric research focus which brings basic and clinical researchers together to facilitate

Huntington's disease science in the human condition. Applicants worldwide proposed projects addressing HD through small clinical studies or donated human samples. This year's winners hail from Scotland, Spain, and the United States.



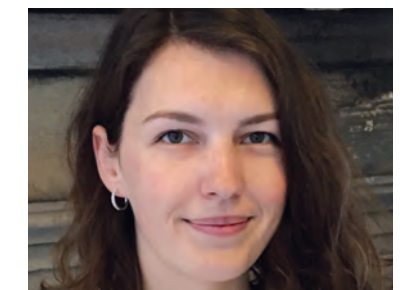
Danielle Larson, MD
*Northwestern University
Feinberg School of Medicine*

Dr. Larson will study whether remote "telemedicine" visits with a neurologist could be just as helpful as in-person visits for an HD patient or family.



Osama Al Dalahmah, MD
Columbia University

Dr. Al Dalahmah will examine how astrocytes, the brain's support cells, change over the course of HD to become harmful versus helpful.



Vilija Lomeikaite, PhD candidate
University of Glasgow

Vilija will work on improving the existing methods to detect an increase in CAG repeats in certain cells of the body and brain during the course of HD.



Ricardo Mouro-Pinto, PhD
*Massachusetts General Hospital
and Harvard Medical School*

Dr. Mouro-Pinto will focus on the biology of CAG repeat expansion in hopes of developing drugs to stop this process.



Saul Martinez-Horta, MsC,
Sant Pau Hospital, Barcelona

Saul will examine what kinds of changes are happening in the brain and blood when HD patients begin to have difficulty with planning and memory.



2019 DONALD A. KING SUMMER RESEARCH FELLOWSHIPS

In April of 2019, four exceptional undergraduate students were awarded HDSA's **Donald A. King Summer Research Fellowships**. These awards are named in honor of Donald King, who served as HDSA Board Chairman from 1999 to 2003 and worked tirelessly to advocate for HD families until his death in 2004. In order to further meaningful discoveries about Huntington's disease and ensure that bright young

scientists are steered towards the field, this program supports undergraduates who have committed their summers to training in an HD research lab. Applications are accepted between December and March each year and are reviewed by HDSA's Scientific Advisory Board. The 2019 Donald A. King Summer Research Fellows completed focused HD research projects under the supervision of senior scientists.



Zach Cook, Brown University
Zach spent the summer working with **Dr. Marc Tatar**, testing effectiveness of drugs in a fruit fly (*Drosophila*) model of Huntington's disease.



Chloe LaRochelle, University of Central Florida
Chloe worked under the guidance of **Dr. Amber Southwell** on a project investigating aggression in HD mice.



Alexandra Putka, Duke University
Alexandra worked in the laboratory of **Dr. Audrey Dickey** to elucidate how altered function of a protein called PPAR contributes to HD pathology.



Colleen Strohlein, University of Pittsburgh
Colleen spent the summer working in the laboratory of **Dr. Robert Friedlander**, to investigate whether phosphorylation of huntingtin protein affects its localization to mitochondria.

2019 BERMAN-TOPPER FAMILY HD CAREER DEVELOPMENT FELLOWSHIPS

As part of HDSA's commitment to developing the next generation of passionate and innovative Huntington's disease scientists, the **Berman-Topper Family HD Career Development Fellowships** provide up to \$80,000 of funding per year for three years to young scientists and clinicians who desire to make HD part of their long-term career plan. These prestigious awards are made possible due to the generosity of the **Berman** and **Topper** families and **CHDI Foundation**. HDSA's Scientific Advisory Board reviewed applications from researchers from all around the world, and HDSA was able to award two scientists the 2019 Berman-Topper Fellowship — **Dr. Lauren Byrne** and **Dr. Nicholas Caron**.

Dr. Byrne is working under the guidance of **Dr. Ed Wild** at University College London. Her project will better prepare the field for future disease prevention studies by researching how early in life we can detect changes in the neurofilament light (NfL) protein in persons with the HD mutation.

Dr. Caron is guided by **Dr. Michael Hayden** at the University of British Columbia. He will investigate novel ways to enhance the delivery of huntingtin lowering antisense oligonucleotides across the blood-brain barrier.



Dr. Nicholas Caron



Dr. Lauren Byrne and mentor Dr. Ed Wild at HDSA's Convention in Boston.

HDSA'S 34TH ANNUAL CONVENTION IN BOSTON SETS ATTENDANCE RECORD



The **34th Annual Huntington's Disease Society of America Convention** was held in Boston, MA on June 27th-29th at the Boston Marriott Copley Place. **With 1,225 guests, the Convention set a new attendance record** breaking the previous record (1,046) in Los Angeles, California held in 2018. The education tracks were jam-packed with workshops from world-class speakers, including Nobel Laureate **Dr. Craig Mello** who delivered the Keynote Address during Saturday's Research Forum.

[Watch recorded sessions at HDSA.org/convention](https://www.hdsa.org/convention)

E.J. Garner and Louise Vetter present the HDSA Person of the Year Award to Alexandra Boothby



HDSA 2019 NATIONAL AWARDS

Woody Guthrie Advocacy Award
Seth Rotberg and
Therese Crutcher-Marin

HDSA Youth Award
Hallie Kile

Researchers of the Year
Dr. Darren Monckton and
Dr. Vanessa Wheeler

HDSA Chapter of the Year
HDSA New Jersey Chapter

HDSA Affiliate of the Year
HDSA Connecticut Affiliate

Inaugural Long-Term Care Award
Sitrin Health Care Center

HDSA Excellence in Care Award
Dr. Samuel Frank

Marjorie Guthrie Award
Patricia McLane and
Morgan McLane

HDSA Person of the Year
Alexandra Boothby

The 34th Annual HDSA Convention was made possible by the generous support of all its sponsors:

PRESENTING SPONSOR

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- Lundbeck

GOLD NONPROFIT SPONSOR

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- Sanofi
- Spark Therapeutics
- UMass Medical School
- Vaccinex
- WilmerHale





HD LEGACY — THE GIFT TO FUTURE GENERATIONS

In response to a growing need to study exactly what Huntington's disease (HD) does to the human brain, **HDSA** and **CHDI Foundation** announced a new collaboration in 2019 called **HD LEGACY** to support brain and other organ donations from families affected by HD who would like to make a vital contribution to research. This new



program encourages the donation of brain and other tissues from HD gene-expansion carriers, at-risk individuals, and healthy family controls. **The Harvard Brain Tissue Resource Center (HBTRC)** will assist interested families throughout the process, and families will bear no costs associated with the donation.

'THIS WEEK IN HD RESEARCH' BLOG

HDSA's **Leora Fox, PhD** provides weekly updates in the **This Week In HD Research** blog. Dr. Fox keeps you up-to-date on HDSA research activities, recently published work about Huntington's disease, historical moments in HD research and more. **Follow the blog at [HDSA.org/blog](https://www.hdsa.org/blog)**

CHARITY NAVIGATOR AWARDS HDSA 4 STARS — ITS HIGHEST RATING — FOR THE FOURTH CONSECUTIVE YEAR

"We are proud to announce Huntington's Disease Society of America has earned our fourth consecutive 4-star rating. This is our highest possible rating and indicates that your organization adheres to sector best practices and executes its mission in a financially efficient way. Attaining a 4-star rating verifies that Huntington's Disease Society of America exceeds industry standards and outperforms most charities in your area of work."

Only 20% of the charities we evaluate have received at least 4 consecutive 4-star evaluations, indicating that Huntington's Disease Society of America outperforms most other charities in America. This exceptional designation from Charity Navigator sets Huntington's Disease Society of America apart from its peers and demonstrates to the public its trustworthiness."

Michael Thatcher, President & CEO, Charity Navigator



COUNTRY STAR CHRIS STAPLETON SUPPORTS HDSA

After being introduced to HDSA's rich musical history and incredible mission, singer-songwriter **Chris Stapleton** donated \$5,000 to improve the lives of people with HD and their families.



COMEDIAN ROD MAN HOSTS HD FUNDRAISER — 'MAIN STREET LIVE'

Comedian **Rod Man** who comes from an HD family, hosted his annual talent show — **Main Street Live** — in Georgia to raise funds and awareness for HD. Rod has appeared on NBC's **Last Comic Standing**. This year his charitable event raised more than \$3,000 to support HDSA's mission.



THE STARS SHINE AT FREEZE HD GALA

On Saturday, September 28th, four hundred guests attended the **5th Annual Freeze HD** at Avalon Hollywood where **more than \$420,000 was raised to support HDSA's fight against Huntington's disease**. This star-studded event was hosted by actor **Lamorne Morris** and honored **Kelsey** and **Scott Porter**. Some notable guests included **Seth Green, Topher Grace, Jason Ritter, Katherine McNamara, Marianna Palka, Kate Miner, Rachel Bilson, Wilson Bethel, Jaime King** and **Allie LaForce**. The event featured incredible live performances from **Brian Logan Dales** and **The Dales Hotel**, **Tyson Ritter** from **The All-American Rejects**, **DJ Skee, DJ Prophet, Emma Hutton, Leslie Powell** and **Scott Porter**. Actor **Will Ferrell** donated \$10,000 to support this wonderful night!

"The 5th Annual Freeze HD was the largest fundraising event ever hosted to support our organization and we couldn't have done it without our incredible honorees, **Scott and Kelsey Porter**, sponsors, event committee and everyone who

attended as well as bid on the amazing auction items," said **Louise Vetter**, HDSA's President and Chief Executive Officer. "Thank you everyone — this was truly a showcase of the extraordinary strength of the HD community."

The incredible auction included exciting trips, signed TV/movie & sports memorabilia, once-in-a-lifetime experiences, exclusive tickets, gaming equipment and so much more! Freeze HD was supported by a wonderful event committee that included **Rachel McAdams, Jason Ritter, Jaime King, Marianna Palka, Simon Helberg, Bryce Dallas Howard, Kenneth and Diane Mayfield, Blake and Jenne Coler-Dark, Brian Logan Dales, Matt and Courtney Hamilton, Jamie Linden, Justin and Kate Miner, Elliott and Tracy Owen, Carly Ritter, Nancy Morgan Ritter, Tyler and Lelia Ritter, Jason Ziven, Angelique Cabral, Jaylen Moore and Britt Logan, Gentile Koosed, Kyle Newman, Adam Seid, Jessica Cain, Emily and Jamie Rodgers and Alana Yankowitz.**

MORE THAN
\$420,000
WAS RAISED
AT THE 5TH
ANNUAL
FREEZE HD
GALA

Special Thanks To Our Freeze HD Gala Sponsors

GOLD SPONSORS

- Genentech
- The Ferrell-Paulin Family Foundation

SILVER SPONSORS

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BRONZE SPONSORS

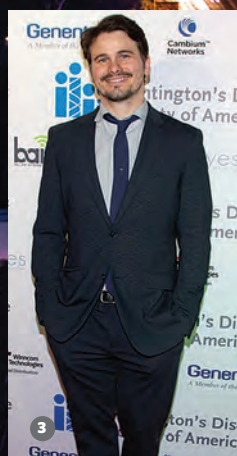
- After Hours Theatre Company
- Amberlee Colson
- California Horizon Pool & Spa
- Educated Nannies
- Fake Empire
- Ferrandino & Son, Inc.
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- The O.C.D. Experience
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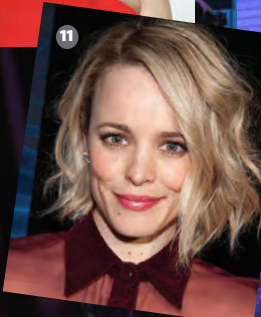
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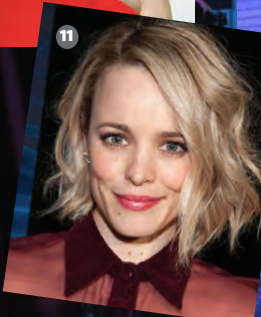
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1. Will Ferrell 2. Ashley Hinshaw and Topher Grace 3. Jason Ritter 4. Scott Porter, Jaime King, Rachel Bilson and Wilson Bethel share a playful moment 5. Kate Miner and Briana Lane 6. HDSA President & C.E.O., Louise Vetter with Freeze HD Gala honorees, Scott and Kelsey Porter 7. Freeze HD Gala host, Lamorne Morris 8. Todd Grinnell 9. Seth Green and Clare Grant 10. Brian Logan Dales performs 11. Rachel McAdams 12. Freeze HD Gala honorees, Scott and Kelsey Porter address the guests

HDSA’S NYC MARATHON TEAM RAISES MORE THAN \$133,000

HDSA’s 2019 New York City Marathon team featured twenty-five runners from twenty different States across the US all willing to take on 26.2 miles to support the fight against HD. **To date, the team raised more than \$133,000 finishing in the top 18 among all NYC Marathon Charity Partners!**

Special thanks to the accounting firm **EisnerAmper** for being the team’s Presenting Sponsor. The team’s fastest runner was **Craig Robinson** who finished with an impressive time of 2:34:55 — good enough for 118th overall! The team’s top fundraiser was **Kari Baker** from Florida who raised more than \$11,000!



HDSA’s 2019 New York City Marathon Team:

Mark Adler, Kari Baker, Jennifer Bandle, Madeline Bolton, Michael Boyle, Aly Boyle, Molly Corse, Samantha Cox, Carlos Fonts, Jonathan Harrison, Emily Lefler, Janine Lind Trembicki, Paula Lintz, Jessica Marsolek, Erin Milek, Jessica Parker, Alycia Patty, Carolyn Plaza, Ricardo Puente, Craig Robinson, Amber Rutledge, Michael Shea, Rod Thompson, Kristen Westdorp and Sara Witzl.

Clockwise from left: Craig Robinson, Samantha Cox, Kari Baker, and Janine Lind Trembicki

‘ALL IN TO END HD’ CASINO NIGHT WITH GUILLERMO



The **‘All In To End HD’ Casino Night** took place on Saturday, June 1 at the Continental Club in downtown Los Angeles. The evening featured a speakeasy venue setting, live music from jazz singer **Andrea Miller**, various gaming tables and an appearance from emcee **Guillermo** from **Jimmy Kimmel Live!** The event successfully brought in 125 guests and raised \$35,000 for our HD community — all while engaging new committee members, potential sponsors and local influencers for next year.

Jazz singer Andrea Miller and Guillermo Rodriguez from ABC’s Jimmy Kimmel Live!

HDSA FILMS DEBUT

In 2019, HDSA produced three powerful short films — **Carol & Richard: A Love Story**, **The Hodgsons**, and **The Vaughns**. All were directed by **Rae Maxwell**. The films are featured on HDSA’s YouTube Channel and each has received thousands of views.

At right, a scene from *The Hodgsons*, produced by HDSA Films.



HDSA Films

‘HERE’S THE DEAL’ VIDEO SERIES

HDSA’s **Jennifer Simpson, LCSW** continues to host **Here’s The Deal**, an online video series that features insightful conversations with members of the HD community. This past year’s topics included **Isolation**, **Family Planning**, **Caregiving While Positive** and **Parenting a Child With JHD**.



Visit HDSA’s YouTube Channel to watch the entire **Here’s The Deal** series.

SEPTEMBER 18: HDSA’S FOUNDER’S DAY OF GIVING

On **September 18th**, HDSA launched **The Founder’s Day of Giving** to pay tribute to our founder, Marjorie Guthrie. It was on September 18, 1967 our organization was founded. In just its first year, Founder’s Day of Giving raised more than \$10,000 to support the first-time attendee **HDSA Convention Scholarship Program**. **Thank you!**



CELEBRITIES RAISE HD AWARENESS

Seth Green, Jason Ritter, Marianna Palka, Kate Miner, Jaime King & Rachel Bilson, Nyambi Nyambi, Wilson Bethel, Scott Michael Campbell and Rachel Nichols are among many more celebrities who continue to generate much-needed HD awareness through **#LetsTalkAboutHD** public service announcements.



HDSA 2019 MISSION REPORTS

RESEARCH

After years of waiting, in 2019 the HD community was rewarded with a spree of potential disease-modifying clinical trials. With such anticipation and demand, the Natural History and GENERATION- HD1 studies from Roche-Genentech, the Precision HD2 trial from Wave Life Sciences, and the Signal study from Vaccinex all completed US recruitment this year, at record speed. While we await results from these studies, the HD research momentum continues. This year, uniQure began the first ever gene therapy trial for HD, and several other companies are moving towards this goal. Recent success in gene therapy for spinal muscular atrophy provides a strong sense of optimism that this approach could alter the course of HD, too. Novartis also announced plans to launch a Phase 2 trial investigating an oral huntingtin-lowering drug.

While the light of hope now shines brighter for all of us, much work remains before HD becomes a thing of the past. That work requires the voices and the continuing participation of HD families. In 2019, HDSA continued to enable families to learn about and participate in HD research, through HD Trial-finder, our research blog and webinars, support of HD Buzz, the international Coalition on Patient Engagement (HD-COPE), and more. The inspiring scientific progress within the HD research community this year gives me confidence that 2020 will bring generations of HD families one step closer to relief.



ADVOCACY

2019 saw positive growth and chance in our advocacy agenda! We were lucky to have Catherine Finley of Thorn Run Partners join us in the fight to pass the HD Parity Act as the leader of our Washington D.C.-based advocacy efforts. In May, Representatives Kinzinger (R-IL) and Pascrell, Jr.(D-NJ) introduced the HD Parity Act in the House alongside their partners Senators Gillibrand (D-NY) and Cassidy (R-LA) in the Senate. The HD Parity Act (HR 2770/S 1476), is a bill that HDSA and advocates have been fighting to pass for a decade, and we are working hard as we can to see this bill cross the finish line this Congress. In July, more than 20 advocates from across the country joined HDSA's President and CEO Louise Vetter to advocate with members of the Senate Finance Committee, asking them to advance the HD Parity Act through committee.



Rep. Adam Kinzinger (R-IL)



Rep. Bill Pascrell, Jr. (D-NJ)



Sen. Kirsten Gillibrand (D-NY)



Sen. Bill Cassidy (R-LA)

EDUCATION

2019 was an exceptional year for HDSA educational efforts. Thanks to a generous unrestricted educational grant from Genentech, HDSA was able to support 59 educational events that ranged from full day conferences to half-day meetings to support group guest speakers. This compares favorably with 2018 when HDSA supported 49 educational events. Our thanks to the creativity and budget savvy of our event organizers who used every one of our grant dollars wisely. In addition to outstanding programming in the areas of care, advocacy and youth, several larger conferences received a clinical trial update from Genentech as well as information about advances in HD research.



DISABILITY PROGRAMS

In 2019, HDSA unveiled its new disability program thanks to the addition of disability attorney, Allison Bartlett, Esq., who specialized in the representation of clients with rare, chronic conditions, like Huntington's disease, to navigate them through the complex disability system. She works directly with families and social workers to provide advice, assistance, and resources for the Social Security disability process. We have assisted and provided educational resources to approximately 91 social worker requests and 222 HD families via phone and email regarding the Social Security disability process and the appropriate next steps for the disability application in the areas including: when to start the disability process, tips for submitting a disability application, health insurance, work credits and disability eligibility, and case specific disability questions. HDSA launched the Disability Chat Webinar Series in September 2019 to cover a wide range of disability topics for families and social workers.



SUPPORT SERVICES

HDSA is proud of the support services that we provide to families throughout the country. Social workers in HDSA Centers of Excellence, Chapters, Regions and other HD clinics assist families in their 47 states. Our social work professional training brought 68 social workers together prior to Convention in Boston. This in-person educational event helps HD social workers provide the best and up to date information on assisting HD families with their concerns. Many families find support and a listening ear at HDSA in-person support groups that are available in many states. Our online support groups are free and open to those around the country. Individual counseling sessions are also offered for free through telehealth services provided by Amwell® (www.HDSA.org/telehealth).



YOUTH PROGRAMS

2019 saw the expansion of HDSA's stable of youth support programs, rolling out our Youth Social Worker Pilot Program and the integration of these two social workers into the world of youth work. In 2019, the HDSA National Youth Alliance (NYA) held their four youth retreats around the country, returning to Pittsburgh and New Orleans and introducing Chicago and Sacramento as new sites. HDSA and the NYA brought nearly 90 young people out to our youth retreats in 2019, providing them with information from experts at HDSA Centers of Excellence, support from social workers, and integrated improv and art therapy workshops. The NYA also funded more than 60 young people to attend HDSA's largest ever National Convention in Boston through full and partial scholarships.



FINANCIALS

STATEMENTS OF FINANCIAL POSITION

AS OF DECEMBER 31, 2019 AND 2018

	2019	2018
ASSETS		
Cash and cash equivalents	\$ 8,337,091	\$ 7,236,088
Pledges and contributions receivable, net	1,221,960	1,338,533
Investments	2,069,844	1,728,039
Prepaid expenses and deposits	167,544	152,770
Property and equipment, net	55,849	47,443
Website costs, net	61,469	8,181
Total Assets	11,913,757	10,511,054
LIABILITIES		
Accounts payable and accrued expenses	101,723	116,344
Accrued compensation	265,315	185,723
Grants payable	1,088,162	1,447,523
Event revenue received in advance	71,174	14,578
Deferred rent obligation	118,993	116,711
Obligation under capital lease	8,536	13,250
Total Liabilities	1,653,903	1,894,129
NET ASSETS		
Without donor restrictions		
Undesignated	2,838,422	1,372,640
Board-operating reserve	1,796,131	1,518,483
	4,634,553	2,891,123
With donor restrictions		
Purpose restrictions	5,144,869	4,950,357
Time-restricted for future periods	230,432	525,445
Perpetual in nature	250,000	250,000
	5,625,301	5,725,802
Total Net Assets	10,259,854	8,616,925
Total Liabilities And Net Assets	11,913,757	10,511,054

NOTE: These Consolidated Statements reflect HDSA's operations for the fiscal years as stated and include all affiliates. Please contact the HDSA National Office for a full copy of the audited financial statements.

CONSOLIDATED STATEMENTS OF ACTIVITIES

YEAR ENDED DECEMBER 31, 2019 WITH SUMMARIZED FINANCIAL INFORMATION FOR 2018

	2019	2018
SUPPORT & REVENUE		
Public donations	4,209,337	3,654,204
Foundation grants and corporate contributions	2,568,769	2,337,869
Federated campaign	271,027	293,299
Special events (net of direct benefit to donors of \$681,911 and \$562,549 in 2018 and 2017, respectively)	4,158,871	4,332,708
Investment income, net	26,227	33,126
Donated services and materials	404,183	788,276
Other income	162,359	79,337
Total support and revenue before net assets released from restrictions	11,800,773	11,518,819
Net assets released from restrictions	0	0
Total Support and Revenue	11,800,773	11,518,819
EXPENSES		
Program services:		
Research	1,753,479	2,641,145
Family services	2,976,990	2,530,727
Education	1,833,920	1,669,701
Community outreach	1,177,664	1,039,072
	7,742,053	7,881,059
Supporting services:		
Management and general	578,718	78,029
Fundraising	1,837,073	1,307,380
	2,415,791	2,091,409
Total Expenses	10,157,844	9,972,918
Increase in net assets	1,642,929	1,545,901
Net assets - beginning of year	8,616,925	7,071,024
Net Assets - End of Year	10,259,854	8,616,925

NOTE: These Consolidated Statements reflect HDSA's operations for the fiscal years as stated and include all affiliates. Please contact the HDSA National Office for a full copy of the audited financial statements.

YOUR HDSA DOLLARS AT WORK

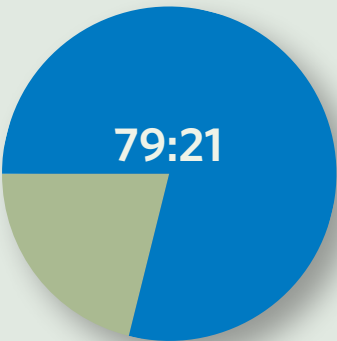
BASED ON AUDITED FINANCIALS FOR FISCAL YEAR ENDED DECEMBER 31, 2019

OVERVIEW

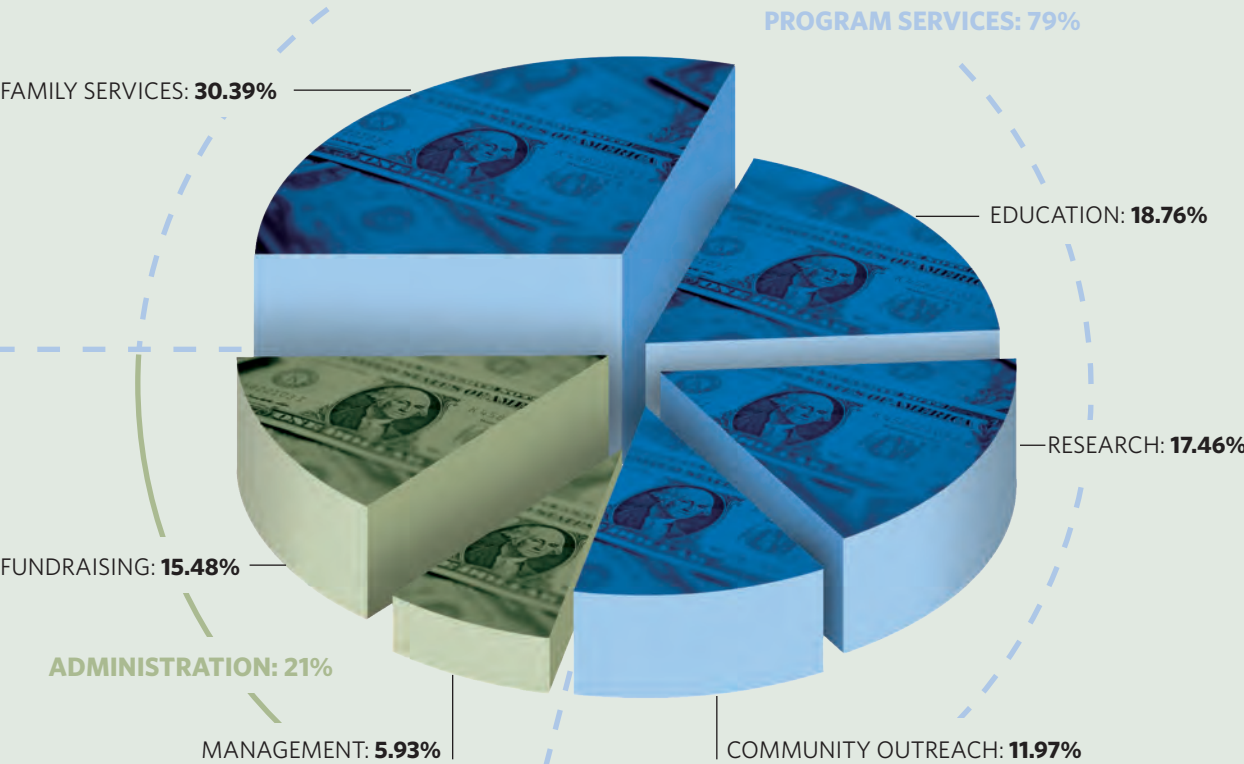
- ▲ Total 2019 revenue of \$11.8 million.
Up from \$11.5 million in 2018.
- ▲ Funded \$2.1 million in new grants.
HDSA Centers of Excellence and research grants.

MISSION RATIO

- ▲ Program Services: 79%
- ▲ Administration: 21%



FUNDS ALLOCATION



THANK YOU HDSA DONORS!

THANK YOU TO OUR DONORS FOR THEIR GENEROUS SUPPORT OF \$1,000 OR MORE

- Anonymous (9)

Ms. Greta K. Abbott

Mr. & Mrs. Bill Addis

Mr. Mark Adler

Mr. James Agnich

Mr. Kamran Alam

Mr. Jeremiah Alexander

Angela & Bernard Allen

Ms. Brenda Allen

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Until the day when scientists find a cure for HD, families across the country require access to the crucial research, care, education, and advocacy programs HDSA provides. The Marjorie Guthrie Society ensures that as we look to the future we'll have the resources we need to continue providing help and hope to the HD community.

By including HDSA in your estate plans as the beneficiary of insurance, real estate, appreciated securities, or retirement plan you can create a legacy of giving that guarantees future generations

will have the vital support they need to confront this devastating illness. With the help of a financial planner, you can arrange your gift in a way that reduces your estate taxes and has the strongest possible impact on the lives of those affected by HD in the decades to come.

To learn more about the Marjorie Guthrie Society, or to inform us of your estate plans to support HDSA, please contact Jamison Skala, Director of National Development, at (212) 242-1968 ext. 235 or jskala@hdsa.org.



HDSA founder, Marjorie Guthrie

Join us in thanking the following individuals who have committed to support HDSA through their estate plans:

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- Norman Baldwin
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- Catherine Hayes & Mark Wiesel
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